

**SSA hearing on Compassionate Allowances for Rare Diseases**  
**Thursday, December 5<sup>th</sup> 2007**  
**Tentative Speech time: 11 a.m.**

**PART ONE: BARBARA (3 min)**

**Introduction**

- Greet Commissioner Astrue, Judge Cristaudo and Dr. Groft.
- Thank panel for opportunity to comment

**Background on HD**

- Basic info on HD and its devastating effects

**Background on HDSA**

- Purpose of HDSA
- Services provided
- Services provided in relation to SSDI/SSI: SWs, Helpline, website

**Experience of HD patients with Social Security processes**

- Length of process, wide range of responses: 8 weeks - > 1 year
- Many experience delays/denials do to multiple referrals and general unfamiliarity with HD on the part of SSA adjudicators/physicians
- SSI
  - Necessity to be at poverty-level has been the most common obstacle

**Why these problems exist**

- Lack of sufficient accurate medical information for evaluation of HD
- Current listings incorrectly emphasize physical listings
  - Countless examples of pHD denials and hardship due to presence of only softer signs

**Centers of Excellence**

- Why Centers were created
- Their structure and function

**PART TWO: Dr. ADAM ROSENBLATT (4-5 min)**

**Centers of Excellence at Johns Hopkins**

- Treatment of HD patients and families at JHU
- HD Research

**Center perspective on difficulties with SSDI application process**

- Common difficulties/reasons for delays
- Medical Inaccuracies of listings
- Personal experience as to the impact these pitfalls in the bluebook have had

**Additional medical criteria that could improve the process**

- How can the criteria be improved
- Any scientific support for these offered criteria

**Concluding thoughts**

**PART THREE: BARBARA (2 min)**

- Potential for SSA partnership with Centers of Excellence and HSG sites
- Take home message(s)